Women and Ischemia Syndrome Evaluation (WISE)
Diagnosis and Pathophysiology of Ischemic Heart Disease
Workshop

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Session 6

1. Topic and Author

Creating A Science-Based Public Education Message on Heart Attack Recognition and Response
Ms. Mary Hand and Ms. Terry Long

2. Where we stand in 2002. Overview/rationale for inclusion of topic.

Accurate and timely diagnosis and treatment of all individuals with acute manifestations of coronary heart disease are major objectives of the National Heart, Lung, and Blood Institute's (NHLBI's) National Heart Attack Alert Program (NHAAP). With the advent of reperfusion therapy, shown to have time-dependent benefits in terms of reducing acute MI morbidity and mortality, the NHAAP was started in 1991 to educate health care professionals, patients, and the public about the importance of rapid identification and treatment of these patients. The Program's advisors recognized the lack of empirical support for a public education campaign to reduce delay for acute MI and focused its initial efforts mainly on hospital (emergency department) and system delays (Hand et al., 1998). The NHAAP published issue papers and reports highlighting: rapid identification and treatment of AMI patients in the emergency department setting, patient and bystander factors associated with delay time, and EMS issues that impact on rapid recognition and treatment. In addition, the program produced papers reviewing technologies used in the emergency diagnosis of patients with acute cardiac disease, and educational strategies to reduce prehospital delay in patients at high risk for heart attack. In 1998, the NHAAP released a report that described the community as the "ultimate coronary care unit," and encouraged all settings where patients may present with a cardiac emergency, to plan for a timely and effective response.

The NHLBI funded the Rapid Early Action for Coronary Treatment (REACT) research program to study the effectiveness of a multi-center randomized controlled, community intervention trial to reduce patient delay from onset of heart attack symptoms, to arrival at the hospital, as well as to evaluate the impact on emergency medical services (EMS) systems and emergency departments, of a public campaign targeting recognizing heart attack symptoms and calling 9-1-1. The trial's design and rationale have been reported in detail (Simons-Morton et al., 1998; Feldman et al., 1998). In brief, 20 communities from five geographically diverse U.S. regions participated in the trial (10 matched pairs), with one community of each pair randomly assigned to comparison (reference) or intervention status to receive an 18-month multilevel educational program following a four-month data collection period. The REACT communities were in Alabama, Louisiana, Massachusetts, Minnesota, North Dakota, Oregon, South Dakota, Texas, Washington, and Wisconsin. REACT results revealed that delay time reduction (from symptom onset to hospital arrival), the primary outcome measure, was not observed in the 10 intervention communities compared with the 10 reference communities. However, in those communities receiving the educational intervention, the odds of EMS use increased steadily and significantly in the intervention communities, with a net 20 percent increase in EMS use in the intervention as compared with the reference communities (Luepker et al., 2000). REACT investigators also reported a number of findings from focus groups and from follow-up surveys of patients discharged from the emergency department or from the hospital after admission for an acute cardiac diagnosis.

The REACT study provided an updated science base in the area of patient-associated delays in recognition and response to symptoms. REACT investigators conducted 34 focus groups with key target groups in five U.S.

regions in 1995 to inform the study's intervention. These focus groups included individuals who had previously experienced a heart attack, those at higher risk for a heart attack (due to the presence of risk factors or diagnosed CHD), and those who were bystanders to someone who had experienced a heart attack. A number of key findings from the groups emerged: There was universally a pre-existing expectation that a heart attack would present relatively dramatically as portrayed in the movies with sharp, crushing chest pain (associated with syncope) such that there would be not doubt that one was occurring. This was in contrast to their actual reported symptom experience, which was a gradual onset of discomfort involving midsternum chest "pressure" or "tightness" with other associated symptoms (e.g., shortness of breath, arm, neck, jaw, back pain; extreme fatigue; lightheadedness, nausea), often increasing in discomfort. The apparent ambiguity of these symptoms due to this "disconnect" between prior expectations and actual experience generally resulted in patient self-evaluation and self-treatment (e.g., a "wait and see" approach), and re-evaluation over a number of hours. Symptoms were often attributed to other pre-existing chronic conditions especially among the elderly with multiple chronic conditions (e.g., arthritis) or sometimes to a common illness such as influenza. Patients who have reported a mismatch between expected symptoms of a heart attack and actual symptoms have been shown to have longer delay times (Zerwic 1998). The minority of those patients who experienced severe presentations, closer to their expectations of a heart attack, tended to seek care more quickly (Finnegan et al., 2000). These factors—uncertainty about symptoms that do not match prior expectations of a dramatic presentation, a tendency to attribute symptoms to other plausible causes, self-evaluation/treatment and reassessment--provide different understanding into the dynamics of patient delay in seeking care for acute MI symptoms, as opposed to the oft expressed explanation of patient "denial." Focus groups also revealed that patients held stereotypes of who is at risk for a heart attack and thus judged symptoms filtered through their own perceived lack of risk. Those perceived to be young and outwardly healthy were judged to be at low risk for an acute MI. Men at higher risk due to single or multiple risk factors regarded themselves as less likely to have a heart attack than their peers because they were under a doctor's care and had made risk-reducing lifestyle changes. Men were also more likely to think that they were "too young" for a heart attack, perceiving it as a phenomenon of the elderly. Perception of one's personal risk was higher if there was a family history of a heart attack, diabetes, current smoker, previous heart attack. Personal risk of a heart attack was low among women who viewed heart disease as predominantly a male problem (Finnegan et al., 2000). Focus groups from REACT also demonstrated that few ever discussed in advance symptoms, responses, actions for a heart attack with physicians, spouses, or family. During the event itself, patients reported consulting with a spouse or family member who supported them in delay and self-treatment. Worsening symptoms often led bystanders to take greater control over the decision to seek care. There was little awareness of the benefits of rapid action and little knowledge of reperfusion treatment or of the benefits of calling EMS/9-1-1 in treating acute MI in the field. The majority of focus group participants did not use 9-1-1 to get to the hospital but were driven by others or drove themselves.

The NHAAP met with its Executive Committee in 1999 (following the reporting of the REACT results at the American Heart Association Scientific Sessions in 1998) to consider what the NHAAP's approach to public education should be in view of REACT's main results. The Committee recommended that based on the REACT results, the NHAAP should avoid a large, expensive public-education campaign but that it should proceed with broadening its scope to include the public, as is the original charge of the Program. They recommended targeting certain higher risk subgroups who had longer baseline delays times and particular educational needs, such as women, the elderly, certain minority groups, notably African Americans, and patients—those seen in the emergency department and discharged or those with diagnosed cardiovascular disease (CVD) who are released from the hospital. They further identified the importance of targeting "communities at risk" which included those with lower SES, a higher percentage of elderly, minority groups and individuals at increased risk of CVD. The Executive Committee further advised that the Program should use the REACT intervention materials, modified for a national audience. It suggested that there was a need to better understand the details of the REACT data, in particular for certain subgroups and to explore multiple and other strategies beyond traditional educational approaches, such as the use of informatics. They stressed focusing on some of REACT's key messages, such as dispelling the myth of a "Hollywood Heart Attack," and emphasizing calling 9-1-1.

During the time that the REACT materials were reviewed and modification plans identified, staff reviewed the

REACT findings as well as results from focus groups and patient follow-up surveys conducted by the REACT investigators to distill salient messages that should be incorporated into a national education program, in the wake of the REACT research program. In developing its educational message for patients about symptoms, the NHAAP reviewed several recent reports of large series of patients, extracting the most common presenting symptoms. This resulted in a message that included chest discomfort that may be more of a pressure sensation than actual pain, other symptoms of discomfort in the arm(s), back, neck, jaw, or epigastrium, accompanied by shortness of breath; diaphoresis, nausea, or light-headedness. The NHAAP is emphasizing the common misconception that the chest discomfort will always be crushing and dramatic in its presentation. The other more commonly associated acute MI symptoms--shortness of breath, a cold sweat, nausea, or lightheadedness—are also important because while chest pain/discomfort is the most frequent chief complaint, not all patients diagnosed with an acute MI (33 percent) will have chest pain on presentation.

The Program felt it was important to emphasize the other associated symptoms along with chest discomfort because survey findings from the REACT research program have shown that while knowledge of chest pain as a component of a heart attack presentation was relatively high—nearly 90 percent of those surveyed--albeit a severe, crushing image, knowledge of other associated heart attack symptoms was less common: arm pain (67 percent aware); shortness of breath, (51 percent aware), sweating, (21 percent aware), and the other acute MI symptoms (Goff et al., 1998).

Staff reviewed the REACT symptom message as well as those used by the American Heart Association (AHA), the American Red Cross, the American College of Cardiology, and the American College of Emergency Physicians to ascertain consistency in the symptoms listing. The NHLBI, in partnership with the American Heart Association (AHA), worked together to craft a common, science-based symptom and action message for the public. Several symptoms were modified from both the REACT and the AHA symptom lists. The revised symptom and action lists as well as several other key messages from REACT research, were included in the "core" heart attack recognition and response message.

The other key messages extracted from the REACT focus group and other survey findings were:

- Emphasize that if for some reason you can't call 9-1-1, have someone drive you to the hospital right away. If you are the one having symptoms, do not drive yourself, unless you have absolutely no other option.

- Dispel the myth of the "Hollywood" heart attack. Some heart attacks are sudden and intense. But most heart attacks start slowly with mild pain or discomfort.

- Explain there may be (usually in addition to chest discomfort): a feeling of being short of breath (i.e., having trouble breathing), sweating; pain in the arms, back, neck, jaw, or shoulders; a feeling of being "sick to your stomach;" or a feeling of being dizzy or weak.

- Promote the notion of "when in doubt, check it out". Usually people are not sure what is wrong or are embarrassed or afraid and wait too long before getting help. The only way to know for sure is to be evaluated in a hospital emergency department.

- Emphasize that one will be taken seriously and treated respectfully if one comes into the emergency department with possible heart attack signs, even if it is a false alarm. Health care providers will reassure you that you did the right thing for coming in, even if it is a false alarm.

- Include the benefits of artery-opening treatment and the importance of getting treatment quickly to stop a heart attack in its tracks. Early treatment can prevent death or severe heart muscle damage that will affect

the quality of life (feeling of vigor).

- Stress that heart attacks are the number one cause of death among women and that the risk increases greatly with age, especially after menopause.

- Encourage talking to family, spouse, and health care providers about individual risk and what to do if faced with possible warning signs of a heart attack. Develop an action plan ahead of time, especially with your health care provider.

- Encourage bystanders to call 9-1-1 if he or she is with someone who has the signs of a heart attack

During 2001, the staff revised and updated the REACT materials, preparing them for national dissemination as a unified campaign, and formed partnerships with national organizations that were committed to helping disseminate the materials. The NHLBI and the AHA launched the campaign in September 2001 urging patients and providers to "Act In Time to Heart Attack Signs" (Faxon and Lenfant, 2001). The campaign urges anyone who feels heart attack symptoms or observes the signs in others to wait no more than a few minutes–5 at most– before calling 9-1-1. Campaign materials point out that Americans can increase their chance of surviving a heart attack by learning the signs and filling out a heart attack survival plan. They also are advised to talk with their doctor about heart attack and how to reduce their risk of having one. The campaign offers a free brochure about heart attack and its signs in English and Spanish, as well as a free wallet card that can be filled in with emergency medical information. Other campaign materials for providers include a Patient Action Plan Tablet containing the heart attack warning symptoms and steps for developing a heart attack action plan, individualized with the patient's name; a quick reference card for addressing common patient questions about how to survive a heart attack, including a palm pilot version, a warning signs wall chart, a small group session lesson plan, and a patient education video. These materials–and others–are available on the "Act In Time" Web page, which can be reached through the NHLBI Web site.

An "Act In Time To Heart Attack Signs" web site was also established to support the launch of the campaign. The NHLBI, in cooperation with the American Heart Association, issued a "Call to Action" that was published in the September 11, 2001 issue of Circulation to issue the call. A joint press conference was held on September 10, 2001 in Washington DC, with the American Heart Association to announce the updated heart attack symptom message and the joint "Call to Action" to raise awareness about the issue. The timing of the Circulation editorial and the press conference was intended to take advantage of the date 9-11 and the important message about calling 9-1-1 in response to heart attack symptoms.

Since the campaign was launched, efforts to market and distribute Act In Time continue in many ways, especially through the project's partners--the American Heart Association, the American Red Cross, and the National Council on the Aging--who worked with the NHAAP in message development (notably the AHA), pilot testing, and co-branding of the campaign materials. These partners have made extensive efforts to integrate the use of Act In Time into existing activities and to encourage intensive and sustained use of the materials in local chapters and networks.

Significant headway has been made in disseminating the campaign messages and materials. Act In Time is now being integrated into AHA's 150 Operation Heartbeat sites across the country. NHLBI produced a comprehensive "Integration Ideas Fact Sheet" to facilitate this process. AHA disseminated the fact sheet and materials through direct mail, special email notices, and other means. As a result, Operation Heartbeat sites are currently using the materials as part of ongoing local activities such as American Heart Walks. Use of Act in Time was even included in the Operation Heartbeat performance plans as a "recommended element." The National Council on the Aging made a commitment to use Act in Time in 1,000 senior centers. These centers serve tens of thousands of clients, including many in high-risk communities. More than 500 centers have already ordered materials and many provided data on how they are being used. The Act in Time Small Group Session has been made an official Red Cross course. The Red Cross sent Act in Time materials to all its 1,200 chapters

nationwide. Using their own resources, they also produced a special course which combines the Act in Time messages with an existing Red Cross course on reducing cardiovascular disease risk. They also developed a special marketing kit to help the chapters promote the class in their communities. The courses are on the Red Cross staff Intranet.

The NHAAP Coordinating Committee organizations are also priority partners for adoption of the messages and materials into their local networks and community outreach efforts. At the February meeting of the NHAAP Coordinating Committee, the Committee members heard presentations on the background of the "Act In Time" campaign, the campaign materials, the campaign launch, and opportunities to disseminate the campaign through their organizational networks. Representatives of organizations on the Education Subcommittee completed tentative plans for informing their organizations of the Act In Time campaign. Since the meeting, marketing flyers were included as part of the annual meeting materials at the American College of Preventive Medicine's 2002 meeting and the American Academy of Physician Assistants, along with a presentation by the representative. The American College of Cardiology has been especially responsive in disseminating information about Act in Time to its members. A special notice was posted at the top of the ACC web site, an email update was sent to members, a notice will be included in ACC News, and the materials will become part of "OSCAR," the ACC database of resource materials.

Finally, all NHAAP Coordinating Committee members received an electronic "Act In Time" Advocacy package (May 2002) that provides them with ready-made tools and ideas for actively participating in the campaign. The package includes: PowerPoint slides; a drop-in article for publication in newsletters, journals, and Web sites; a drop-in text announcement for insertion into publications; a camera-ready display for insertion by the organizations' advertising department or publisher; ready-made Web link text, buttons, and banners; HTML and text e-mail templates for an organization's online network; and ideas for advocating act in time.

Beyond the partners and the Coordinating Committee, since the launch of the campaign, the NHLBI has mailed the marketing flyer to 100,000 hospitals, community clinics, managed care organizations, worksite programs, and other groups. The Department of Health and Human Services Office of Women's Health sent a special e-mail notice and a sample of the campaign materials to their national network of Centers of Excellence in Women's Health and the National Community Centers of Excellence across the country. A joint marketing letter and special mailing was done for the site coordinators of the Association of Women's Health, Obstetric and Neonatal Nurses.

The Internet and exhibits are also being employed to market the Act In Time campaign. In terms of media relations, a new press release promoting the materials was sent out during Heart Month in February, and went to health and consumer magazines, health columnists, Sunday Supplements, and other outlets. A release targeting African American and Hispanic outlets was also done in early 2002.

3. Current challenges and the most important issues for future research

The heart attack symptom message in the Act in Time to Heart Attack Signs campaign is geared to both men and women. Little is said about acute MI symptoms in women only. This workshop represents an important step in reviewing data and defining a gender-specific symptom message for women. The current challenge is to arrive at a science-based message that can be used to amplify existing campaign messages and materials. Future research is needed to explore such issues as whether women perceive symptoms differently from men, cultural and educational differences that may influence how symptoms are expressed, and the effect on symptoms of such conditions as age, race, and associated conditions such as diabetes.

4. Current challenges in the areas of communicating messages to health care community, patients and the public

Mass media messages about heart attack symptoms in women are quite mixed. They often report that women's symptoms are "atypical" only, ignoring altogether the common symptom of chest discomfort or pain present in a

large proportion of women and men (Goldberg et al., 2000). Further confounding communication is that symptoms that are called "atypical" are often symptoms that are commonly associated with an acute coronary syndrome in both men and women such as arm/neck/back/epigastric discomfort, dyspnea, diaphoresis, and nausea (Canto et al., 2000; Canto et al., 2002). Furthermore, the atypical symptoms list often varies from story to story. In fact, the media talk so much about alternative symptoms and "women being different" that the public and health care providers may ignore chest pain and its commonly associated symptoms, as valid heart attack symptoms in women. Another problem in the lay press is that when "symptoms of heart disease" are discussed, a distinction is seldom made between symptoms of stable coronary disease, such as new onset angina, and symptoms of an acute MI. It may be better to communicate the range of symptoms and be clear about what stage of the disease is being addressed. The challenge is to develop a clear, science-based symptom message articulating what symptoms men and women have in common, what symptoms may be unique, and where more research is needed. This will give the media an opportunity to report a "course correction" about the issue, refining and expanding on previous communications that emphasized the atypical symptoms only. For health care providers, the challenge is to raise awareness about a science-based heart attack symptom message in women and that the accepted message about differences may not be accurate.

5. Translating new findings to improved diagnosis and treatment/saving lives.

Following the workshop, attention must be given to translating new findings and science-based symptom messages into educational materials and using marketing and communications techniques and channels to reach the public, patients, and health care providers. The opportunity exists to integrate the new symptom messages into two relevant NHLBI campaigns–Act in Time to Heart Attack Signs, and the new campaign on heart disease and women entitled, The Heart Truth. In addition to creating a wide range of educational materials for various audiences, both campaigns have fostered partnerships with voluntary, medical and other organizations which can contribute to effective and lasting message dissemination and utilization.

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